Tidsskriftet Tidsskrift for Den norske legeforening

Autism diagnoses in school-age children in southern Trøndelag 2016–2019

ORIGINAL ARTICLE

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Background

We have previously reported a significantly higher prevalence of autism spectrum disorders in southern Trøndelag among preschool children with mothers from a different national background than Norway. In this study, we wanted to investigate whether, in the same period and in the same geographic

area, there was also an excess prevalence among school-age children. Additionally, we wanted to identify psychiatric and developmental comorbidities.

Material and method

We carried out a retrospective review of the medical records of children between 10 and 16 years of age who had been diagnosed with autism in the period 2016–19.

Results

Out of a sample of 125 children, 18 had mothers with a different national background. This gave an incidence rate of 0.18 %, against 0.12 % for children with mothers born in Norway (relative risk 1.5; 95 % confidence interval 0.87 to 2.50, $p = 0.11$). A total of 74 children had been diagnosed with at least one other developmental disorder or psychiatric condition, most commonly ADHD, before they received the autism diagnosis. In four children, the autism spectrum disorder was accompanied by an intellectual disability.

Interpretation

Maternal national background appears to be a less significant factor among school-age children than among preschool children who receive an autism spectrum diagnosis, and age at the time of diagnosis should be specified in studies on autism in children and adolescents. Psychiatric comorbidity and other accompanying developmental disorders may suggest shared aetiological factors or increased vulnerability in cases of undiagnosed autism in children.

Main findings

There was no excess prevalence of autism diagnoses in school-age children of mothers with a different national background.

The incidence rate of autism diagnosis was 0.18 % in children of mothers with a different national background than Norway, and 0.12 % in children whose mothers were born in Norway (relative risk 1.5; 95 % confidence interval 0.87 to 2.50).

Of the school-age children who took part in the study, 22 % had received other diagnoses at the same time as their autism diagnosis.

Of the school-age children who were diagnosed with autism, 59 % had already been diagnosed with one or more neuropsychiatric conditions.

The prevalence of autism spectrum disorders is rising, and the reason why is not clear (1). Changes to the diagnostic criteria and increased awareness of the diagnosis may explain much of the increase, but a genuine rise in prevalence cannot be ruled out (2).

Autism spectrum diagnoses cover a broad range of conditions characterised by early deficits in mutual social interaction and patterns of communication, repetitive sensory motor behaviours and restricted interests (3). The prevalence varies with geographical area (4, 5). It is difficult to compare prevalence rates for autism spectrum diagnoses, for example because data are obtained from a variety of sources, including diagnostic registers and population-based studies (6).

There is reason to believe that children who receive an autism diagnosis at the preschool stage have a heavier symptom load than children who receive a referral and are diagnosed at a later stage. Leader et al. found that children with autism and an accompanying intellectual disability received their autism diagnosis significantly earlier than those whose intellectual ability was in the normal range (7). This may also be the case in Norway. A Swedish study that investigated the diagnostic subgroups of childhood autism and Asperger syndrome separately, found a higher risk of childhood autism, but not of Asperger syndrome, when the maternal national background was a country other than Sweden (8). Of the children with childhood autism, 67 % had an accompanying intellectual disability, but it was not reported how many of these had a mother with a different national background. Another Swedish study showed something similar: There was an increased risk of autism in children with comorbid intellectual disability whose parents had an immigrant background, but the risk of autism was lower if there was no comorbid intellectual disability (9). A Finnish study that focused on children with Asperger syndrome found a lower risk when both parents had a different national background (10).

Most studies that investigate the prevalence of autism spectrum disorders do not specify the age of the child at the time of diagnosis (4). The prevalence of autism spectrum disorders in children and adolescents born in Norway in the period 2001–2016 to Norwegian-born mothers was 0.23 % at the age of 2–5 years and 1.54 % in the 14–17 age group (11, Table 3.5). This means that there is an almost seven-fold increase in prevalence between preschool age and adolescence. Similar figures for children whose mothers have a different national background did not show a similarly rising ratio with increasing age.

A recent Norwegian study focused on several developmental disorders among children born in Norway to immigrant parents (12). This study found a higher prevalence of autism spectrum diagnoses, particularly in preschool children. This matches our earlier findings in respect of preschool children in southern Trøndelag diagnosed with an autism spectrum disorder (13). Clinically, it appears that the same excess prevalence does not apply for children who are diagnosed at school age. The purpose of this study was therefore to establish the incidence of autism spectrum diagnoses in relation to maternal national background in school-age children, and to identify psychiatric and other neurodevelopmental comorbidities.

Material and method

The study was a retrospective review of the medical journals of children aged 10–16 years in the catchment area of St Olav's Hospital (southern Trøndelag) in the period 2016–2019 who had been diagnosed with an autism spectrum disorder, either by the Child and Adolescent Mental Health Services or the Child Habilitation Unit. We identified children/adolescents who were of the right age during the relevant period, all of whom were sent information about the study and their right to be excluded. If they were over 16 years of age when the letter was sent out, it was addressed to them. If they were 16 years or younger, the letter was addressed to their parents. The study was considered by the Regional Committee for Medical and Health Research Ethics, Central Norway (Application ID 353116). Referring to the Data Protection Officer's evaluation of the earlier study on preschool children (13), the Research Committee considered that this study was not subject to approval by the Data Protection Officer.

Data obtained from medical records included age, sex, country of birth, subcategory of autism diagnosis (ICD-10 diagnosis codes F84.0 Childhood autism, F84.1 Atypical autism, F84.5 Asperger syndrome, F84.8 Other pervasive developmental disorders and F84.9 Pervasive developmental disorder, unspecified), other neuropsychiatric diagnoses (chapter V of ICD-10 for mental and behavioural disorders, F90 Hyperkinetic disorders and F95 Tics), intellectual disabilities (ICD-10 diagnosis codes F70-F72) and neurological disorders. We also recorded when the various diagnoses were given, by which service, and maternal national background. Population data for St Olav's Hospital's catchment area, southern Trøndelag, were obtained from Statistics Norway.

The incidence rate was calculated as the number of children who received a diagnosis divided by the total number of children of the same age in the population in the relevant period. We reported a 95 % confidence interval (CI) for Relative Risk in Stata 18 and used a two-sided significance level 5 %.

Results

We identified a total of 136 children/adolescents who met the criteria. Of these, ten declined to participate. It proved impossible for other reasons to obtain the medical records of one child. The sample therefore consisted of 125 children, of whom 93 (74 %) were male. Of these, 107 had a mother born in Norway while 18 mothers had a different national background (including six mothers from European countries other than Norway and Russia). This group included nine children who were either adopted from a country other than Norway, or who were born abroad and had moved to Norway with their families. The risk of an

autism spectrum diagnosis was 1.5 times higher (95 % confidence interval 0.87 to 2.50) for the children of mothers with a different national background. This difference was not statistically significant (p = 0.11) (Table 1) (14, 15).

Table 1

Incidence rates for autism spectrum diagnoses in school-age children (10–16 years) in southern Trøndelag in the period 2016–2019, by maternal national background (14, 15).

		2016	2017	2018	2019	Total
All diagnosed children (*N*)		28	33	31	33	125
Total population (*N*)		25 205	25 443	25 877	26 198	102 713
Children of mothers born in Norway	Diagnosed (*n*)	22	30	27	28	107
	Population (*n*)	22 979	23 005	23 213	23 340	92 537
	Incidence rate (%)	0.10	0.13	0.12	0.12	0.12
Children of mothers with a different national background	Diagnosed (*n*)	6	3	4	5	18
	Population (*n*)	2 226	2 428	2 664	2 858	10 176
	Incidence rate (%)	0.27	0.12	0.15	0.17	0.18
Incidence rate for children of mothers with a different national background / children of mothers born in Norway		2.8	0.9	1.3	1.5	1.5

The study's mean age at the time of diagnosis was 12.6 years. Of the children in the sample, 106 (85 %) had been diagnosed by the Child and Adolescent Mental Health Services, or in hospital, while 19 children (15 %) had been diagnosed by the Child Habilitation Unit. The most frequent diagnosis was Asperger syndrome (of these, 59 children had been diagnosed by the Child and Adolescent Mental Health Services, 9 by the Habilitation Unit) and unspecified pervasive developmental disorder (44 and 8 respectively).

A total of 74 children (59.2 %) had been diagnosed with one or more neuropsychiatric disorders before they were diagnosed with an autism spectrum disorder. This was most commonly ADHD (n = 51), followed by language disorders and intellectual disabilities, anxiety and obsessive-compulsive disorders (Table 2).

Table 2

Existing neuropsychiatric diagnoses in 74 of 125 school-age children (10–16 years) who were diagnosed with an autism spectrum disorder in southern Trøndelag in the period 2016–2019.

Diagnosis code (ICD-10)		Number (*n*)
F20–29 F30–39	Schizophrenia, schizotypal and paranoid personality disorders Mood disorders	6
F40–48	Neurotic, stress-related and somatoform disorders	15
F80–83	Developmental disorders (of speech and language and general intellectual disabilities)	19
F90	Hyperkinetic disorders (ADHD)	51
F91–94	Behavioural and emotional disorders in childhood	13
F95	Tics	7

A total of 27 children (22 %) received additional diagnoses, most commonly ADHD, at the same time as being diagnosed with an autism spectrum disorder (n = 19, other data not shown). Four of 125 children were also diagnosed with an intellectual disability (with or without an accompanying neurological disorder, data not shown).

Discussion

This study appears to suggest that there is no excess prevalence of autism spectrum disorders in children of mothers with a different national background if they are diagnosed at the age of 10–16 years. This differs from the findings of our earlier study where we established significant excess prevalence of autism in preschool children of mothers with a different national background (13). Children who received an autism spectrum diagnosis while of school age were generally diagnosed with either Asperger syndrome or unspecified pervasive developmental disorder and their intellectual ability was, as expected, most often in the normal range.

These findings are in line with earlier studies that similarly did not establish a higher prevalence of autism spectrum disorders in children aged between 10 and 16 from an immigrant background and with normal cognitive abilities (8, 9). Magnusson et al.'s study indicated that autism with and without an accompanying intellectual disability may have different aetiologies and that these groups should therefore be studied separately (9). Because most autistic children with developmental comorbidity are diagnosed at the preschool stage, their aetiology may differ from that of children who receive an autism spectrum diagnosis at a later stage. Morinaga et al. discuss potential causes of an elevated

risk of autism spectrum disorders in immigrant families (16). Some of these are linked directly to the mother's migration, which is why we have chosen to specify how many children were born in a country other than Norway.

Health-seeking behaviours

Studies have shown that young autistic children of immigrant parents have a heavier symptom load than those from a Norwegian background, which may affect the approach to seeking help from the health service (1, 17). However, we have little knowledge about the health-seeking behaviours of parents with a different national background and children with neurodevelopmental disorders. In 2020, a Swedish study examined parents from diverse cultural, ethnic and language backgrounds, and found that their backgrounds did not affect their behaviours when seeking help with autism symptoms in their own children (18).

The study of preschool children from Trøndelag also did not suggest this (13). Hansen et al. found that ADHD occurred less frequently among children of parents from an immigrant background and discussed the extent to which this might be due to the parents' health-seeking behaviours, understanding of the symptoms or other cultural issues (12). Can similar factors be significant in cases of autism spectrum disorders in children whose cognitive ability is in the normal range?

Comorbidity

In our cohort, 59 % of the children had received one or more neuropsychiatric or psychiatric diagnoses, most commonly ADHD, before they were diagnosed with an autism spectrum disorder. We know that children with autism are at considerable risk of neuropsychiatric comorbidity (19–21). Kiselev et al. described in a study from 2020 that 65 % of those with an autism diagnosis had one or more accompanying neuropsychiatric diagnoses (20). We know of several shared genetic vulnerability factors, as well as shared environmental factors, that may predispose to several neurodevelopmental disorders (22–24). Furthermore, apart from the fact that many with autism have accompanying neuropsychiatric disorders, we can observe similar symptoms – including when patients have no comorbid diagnosis. In a study of adults with ADHD, Hayashi et al. found that 23.3 % scored above the autism threshold value in the Autism Diagnostic Observation Schedule (25).

The fact that many children receive other psychiatric diagnoses first, raises the question of whether this could have been avoided if they had received the autism diagnosis at an earlier stage and therefore would have received better adaptive support and more understanding. There are few studies that describe comorbidity in relation to age at the time of diagnosis. For a long time, the ICD-10 guidelines precluded the possibility of ADHD comorbidity. This may have led to under-reporting and can have influenced numbers in respect of the concurrent prevalence of these diagnoses. Rim et al. investigated this in a Korean register study and found increased prevalence of psychiatric comorbidity (except psychotic disorders) in people who received the autism diagnosis after the age of five (26).

The Autism Phenome Project followed up 75 children who were diagnosed with autism at the age of 2–3.5 years (27). This study found increasing severity of autism symptoms when the children developed comorbid psychiatric disorders. Of these children, 21 % met the criteria for an anxiety diagnosis at the age of 11, and a considerable proportion also experienced attention difficulties (28). Could it be that comorbid disorders amplify autism symptoms in children who at a younger age did not meet the diagnostic criteria? Or does this suggest that the aetiology of autism spectrum disorders has a different cognitive and emotional profile depending on age at the time of diagnosis (29)?

Strengths and weaknesses of the study

It is a strength of our study that we have a relatively complete cohort, in that 92 % of patients who met the criteria are included in the sample. This gives us a representative picture of school-age children in the relevant cohort. The size of the study is a weakness, as is the risk of false-negative findings (Type 2 errors). It is also possible that a larger geographical area and newer data would have increased the generalisability of the findings, and that a prospective study design could have provided more accurate data; we could for example have recorded maternal country of birth rather than national background. It is also a weakness that we did not include information about socio-economic status or genetic findings. This could have given us a more nuanced picture and will be important to include in future studies.

Conclusion

Based on the discrepancy between the findings of the two studies from Trøndelag, we believe it is important to specify age at the time of diagnosis in future autism studies. We also believe that there is reason to study aetiological factors and comorbidity separately based on age at the time of diagnosis.

The article has been peer reviewed.

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Publisert: 11 December 2024. Tidsskr Nor Legeforen. DOI: 10.4045/tidsskr.24.0259
Received 7.5.2025, first revision submitted 24.9.2024, accepted 28.10.2024.